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Carruthers, H, Gomersall, T and Astin, F

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Title: The work undertaken by mechanically ventilated patients in Intensive Care: a qualitative meta-ethnography of survivors' experiences

A short running title: Surviving mechanical ventilation

Authors:

- Helen Carruthers, MSc, H.Carruthers@salford.ac.uk, Lecturer in Physiotherapy, School of Health Science, University of Salford, Salford, UK.
Tel: 0161 295 0034*
- Tim Gomersall, PhD, T.Gomersall@hud.ac.uk, Senior Lecturer in Psychology, School of Human and Health Sciences, University of Huddersfield, Huddersfield, UK.
- Felicity Astin, FESC, PhD, F.Astin@hud.ac.uk, Professor of Nursing and Applied Health Research, School of Human and Health Sciences, University of Huddersfield and Calderdale and Huddersfield NHS Trust, Huddersfield, UK.

* corresponding author

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Declaration

The authors have no past or present affiliation with any parties who would have an interest in the outcome of this review that could constitute a conflict of interest.

Abstract

Background: Mechanical ventilation is a routine intervention for the critically ill but patients' experiences of this intervention are largely hidden from clinicians. A comprehensive understanding of Intensive Care Units survivors' accounts is required to provide health professionals with evidence about the patients' experience to deliver patient-centred care.

Objectives: To synthesise qualitative findings from international studies to understand Intensive Care Unit survivors' experiences of mechanical ventilation, clarify the components of patient-centred care from the patient perspective and understand what can be done by health professionals to improve care processes.

Design: A meta-ethnography of qualitative evidence following ENTREQ recommendations for reporting systematic reviews.

Data Sources: Eight databases (MEDLINE, AMED, CINAHL, PsychINFO, Scopus, WileyOnline, PubMed Central, TRIP) were systematically searched using a piloted strategy described in a published protocol. Searches were completed on 31.8.16 and no date restrictions were placed. Searches were updated on 25.4.17.

Review Methods: Two researchers independently reviewed studies against pre-determined inclusion criteria to assess their eligibility. Studies were included if they reported on the adult patient experience of mechanical ventilation and used qualitative data collection and analysis methods. All included studies were quality appraised. Participant quotes and concepts, described within the categories and themes of published studies, were extracted by one reviewer and coded by two reviewers. A process of constant comparison, which is central to meta-ethnography, facilitated the re-interpretation of data by a team of researchers to generate the final qualitative synthesis. The Enhancing Transparency in Reporting the Synthesis of Qualitative

(ENTREQ) statement was used to ensure that all synthesis stages were comprehensively reported.

Results: Findings from 38 studies, with 608 participants, informed a patient-centred trajectory model; three overlapping stages; alienation, hidden work and recovery characterised the experiences of mechanical ventilation survivors. Health professionals could positively influence the patient experience by promoting ‘trust’ and being vigilant so that patients felt ‘safe’. Care provision that promoted ‘personalisation’ helped participants to retain their identity as unique human beings.

Conclusions: For the first time the pooling of qualitative findings from international studies, using meta-ethnography, has provided a patient-centred model of mechanical ventilation survivors’ experiences of their care processes. Patients may actively engage or passively endure the treatment burden associated with mechanical ventilation.

Keywords

Critical care; mechanical ventilation; patient experience; qualitative synthesis, care processes, meta-ethnography

What is already known about the topic?

- Patient-centred care for mechanically ventilated patients in the Intensive Care Unit is challenging due to the patients' communication difficulties making their care needs hard to determine.
- Patient centred care in Intensive Care Units has generally been conceptualised using the perspectives of health professionals rather than patients.
- Published qualitative studies about patients' experiences of mechanical ventilation in Intensive Care Units exist but findings have not been pooled, using meta-ethnography, to draw out the key implications for practice, policy and education.

What this paper adds

- A patient centred trajectory model has been developed that explains three stages patients experience during mechanical ventilation and highlights how the 'personalisation of care' and 'trust' in health professionals influences care experiences.
- Cognitive and physical 'work' is necessary for patients to cope with the physical sensations and emotional sequelae of mechanical ventilation in Intensive Care settings, and patients can view their experiences to generate either positive or negative meaning.
- Findings illustrate the 'hidden work' that patients do during mechanical ventilation and weaning; this evidence will enable health professionals to strengthen patient-centred care and develop supportive nursing interventions.

1. Introduction

An important part of evaluating the way in which healthcare is provided to patients and their families is to assess the quality of care processes. Care processes include the acceptability of health professional-patient communication and interactions as well as the care that is received (Donebedian, 2005). Patients cared for in Intensive Care Units do not usually have the opportunity to provide direct feedback on their experiences of care processes. More often than not they are unable to communicate as they are sedated and ventilated rendering them unable to verbally communicate their care needs and preferences (Carruthers et al, 2017). Therefore, we have rather limited information about the patient experience of Intensive Care Unit care processes which represents an obstacle to both person-centred care and quality improvement initiatives. Most importantly the care processes that patients receive in hospital are known to be linked to their health outcomes (Anhang Price et al, 2014).

If we consider Intensive Care Unit survivors psychological outcomes it is noteworthy that many report negative emotions and psychological distress (Engström et al, 2013; Khalaila et al, 2011). It is estimated that 28% of Intensive Care Unit survivors report significant depressive symptoms (Davydow et al, 2009) and 14-27% post-traumatic stress reactions (Rattray & Hull, 2008). Moreover, a high level of emotional distress in Intensive Care Unit patients is a predictor of post-traumatic stress disorder (Wade et al, 2012). This suggests that Intensive Care Unit care processes may save lives but also contribute to poor psychological outcomes for survivors.

A common care process delivered in Intensive Care Units is mechanical ventilation. Whilst it is lifesaving, mechanical ventilation survivors often report negative emotions and psychological distress during recovery (Engström et al, 2013; Khalaila et al, 2011). For this reason, we chose to focus upon understanding patients' experiences of mechanical ventilation to clarify the components of patient-centred care from the patient perspective, and understand what can be done by health professionals to improve care processes. In this way mechanical ventilation can potentially be delivered in a way that is more acceptable to patients which may reduce their emotional distress.

Qualitative studies that explore the patient experience of mechanical ventilation in the Intensive Care Unit setting have been published but appear to have had little direct impact on enhancing patient-centred care or informing clinical policy or health professional education. A recent concept analysis of the key components thought to exemplify patient-centred care in Intensive Care Unit settings reported that patient identity, compassionate and professional presence, and biomedical practice were important (Jakimowicz & Perry, 2015). Whilst the model provides a useful start, less than half of the included studies describe the patient perspective (Jakimowicz & Perry, 2015). Therefore, the model presents a view of Intensive Care Unit patient-centred care that focuses more upon the opinion of the health professional rather than the patient.

Qualitative syntheses offer an opportunity to systematically bring together findings from several studies to provide a robust account that explains the patients' experiences of healthcare processes such as mechanical ventilation. When viewing the

body of literature as a whole, new interpretations can be developed (Sandelowski & Barroso, 2006). A rigorous synthesis of multiple qualitative studies can increase the importance, significance and overall contribution of qualitative research to the clinical evidence base that informs healthcare provision, health professional education, policy and clinical guidelines (France, Ring & Noyes 2015).

We located two qualitative syntheses that reported on the patient perspective of mechanical ventilation in Intensive Care Unit settings (Carroll, 2004; Baumgarten & Poulsen, 2014). The main focus of the first synthesis was the experience of being non-vocal rather than the wider experience of mechanical ventilation (Carroll, 2004). Participants described feeling a loss of control and experienced negative emotional responses as a result of being unable to communicate (Carroll, 2004). The second synthesis only included studies published in Nordic countries making it somewhat limited (Baumgarten & Poulsen 2014). The conclusions from this meta-synthesis described the vulnerability of mechanically ventilated patients, consisting of anxiety, fear and loneliness and the importance of staff being present and supportive.

Given the gap in the current literature, an updated synthesis of international studies of the patient experience of mechanical ventilation in Intensive Care Units is warranted. The purpose of this study was to systematically review and synthesise qualitative findings from international studies to better understand Intensive Care Unit survivors' experiences of mechanical ventilation, clarify the components of patient-centred care from the patient perspective and understand what can be done by health professionals to improve care processes. A comprehensive understanding of the patient experience of mechanical ventilation in Intensive Care Units is important to inform clinical

practice, policy, health professional education and models of person centred care in this unique care setting.

2. Methods

2.1 Design

A qualitative meta-synthesis is an interpretive analytical technique in which findings reported from primary research are used as a foundation for a deeper understanding of phenomena (Finfgeld, 2003). There are several approaches to qualitative synthesis and one of these is meta-ethnography (Noblit & Hare, 1988). Using this inductive approach, findings from individual studies are re-interpreted, rather than aggregated, to develop a unique synthesis. The construction of the final synthesis gives a 'whole' that is greater than the sum of its parts (Strike & Posner, 1983) with potentially greater explanatory power than the individual studies alone (Noblit & Hare, 1988). This approach was chosen because it is commonly used in health-related research (Hannes & Macaitis, 2012) and is useful for developing concepts, models and theories (Noblit & Hare, 1988).

A study protocol was developed which clearly describes the synthesis stages and is registered on an International Prospective Register of Systematic Review Protocols (PROSPERO) which is freely accessible at https://www.crd.york.ac.uk/prospero/display_record.asp?ID=CRD42017064549 . The Enhanced Transparency of Reporting the Synthesis of Qualitative Research statement (ENTREQ) (Tong et al, 2012) was applied (see supplementary data) to ensure that all stages of the synthesis were comprehensively reported allowing the transparent assessment of the methodological rigour of the synthesis.

2.2 Inclusion and Exclusion criteria

Table 1 shows the inclusion criteria and MEDLINE search strategy. Inclusion criteria were refined using the PICOS search tool (Methley et al, 2014) and a full search strategy is available as supplementary data. In summary, studies were included if they used qualitative methodology to explore the patient experience of mechanical ventilation and related interventions (e.g. endotracheal or tracheal suction) in an Intensive Care Unit setting.

Table 1: Inclusion criteria

S: Sampling strategy – A comprehensive sampling strategy was undertaken attempting to identify all relevant studies investigating the topic.
T: Type of study – Any kind of qualitative study that report on findings from research involving both qualitative methods of data collection and data analysis.
A: Approaches – Electronic search strategy (see below), citation search of all possibly relevant reviews, electronic hand-search of <i>Qualitative Health Research; Patient Education & Counselling; Nursing in Critical Care; Social Sciences & Medicine journals</i> .
R: Range of years – No restrictions on the electronic search strategy and citation search. The electronic hand search of journals from 2000 until search completed. Searches were completed on 31.8.16 and updated for key databases (Medline and CINAHL) on 25.4.17.
L: Limits – English, published peer-reviewed material
I: Inclusion and exclusions – Participants: Adults (aged 18 or over). Intervention: Participants receiving mechanical ventilation and associated essential treatments including but not restricted to endotracheal and tracheostomy intubation, suction and weaning from mechanical ventilation. Continuous Positive Airways Pressure, non-invasive ventilation (i.e. patients were not intubated) or long-term tracheostomy care beyond the acute care setting were excluded. Comparator: N/A Outcome: The patient experience of mechanical ventilation investigated using qualitative data collection methods.

T: Terms used – The search strategy for MEDLINE is outlined below. This was adapted for use across eight databases (see supplementary data).

1. MeSH heading: Critical Care
2. TX ‘mechanical ventilation’ OR TX tracheo?tomy OR TX endotracheal*
OR TX intubation OR TX suction
3. TX qualitative OR TX interview* OR TX findings
4. #1 AND #2 AND #3

E: Electronic sources – MEDLINE, AMED, CINAHL, PsychINFO, Scopus, WileyOnline, PubMed Central, and the TRIP database

2.3 Search Strategy

A systematic and comprehensive literature search was completed to identify all relevant published articles. Multiple search approaches were piloted due to the difficulty in identifying relevant qualitative studies (Campbell et al, 2011). An information technologist led the development of the electronic search strategy. The final version was adapted for use across eight databases (table 1). The search terms chosen were deliberately broad, as recommended in Cochrane guidance (Booth et al, 2011), to support a sensitive search strategy. To support the robustness of the search key qualitative journals were electronically hand-searched and citation tracking of relevant reviews completed from the searches (table 1). Key qualitative journals were identified in discussions between the authors as those that publish high quality qualitative health research (*Qualitative Health Research, Patient Education & Counselling, Social Sciences & Medicine*), or with a focus on critical care (*Nursing in Critical Care*). Searches were completed on 31.8.16 and updated for key databases (Medline and CINAHL) on 25.4.17.

2.4 Study selection

The selection of studies followed two phases:

- The review of titles and abstracts retrieved against the predetermined inclusion criteria (table 1) by two reviewers (HC & TG) and categorised as ‘possibly relevant’ or ‘clearly not relevant’.
- Full texts of ‘possibly relevant’ abstracts were obtained, scrutinised and classified as ‘relevant’, ‘definitely irrelevant’ or ‘unsure’ by two independent reviewers (HC & TG). Disagreements were resolved by a third reviewer (FA).

2.5 Quality appraisal

In a meta-ethnography a key focus of appraisal concerns the relevance of the study to the overall synthesis (Tong et al, 2012). That said it is important to assess the quality of the included studies to evaluate the extent to which they reflect the key principles that underpin qualitative research. The Critical Appraisal Skills Programme (CASP) (CASP, 2017) was used for this purpose as it addresses key underpinning principles and assumptions such as rigor, trustworthiness, and reflexivity (Hanne & Macaitis, 2012). Articles were divided between the research team and appraised. A sample of 20% (seven) of the included studies was independently rated by two researchers (interrater reliability was 0.46). Studies were not excluded on the grounds of quality as even weaker quality studies are thought to potentially contribute important concepts to a synthesis (Pawson, 2006). However, an overview of the quality of the included studies helps to support the credibility of the final synthesis.

2.6 Data extraction

Data on study characteristics (aims, methodology, theoretical perspective, sampling, data collection, analysis and interpretation) were extracted and transcribed into a Microsoft Excel spreadsheet by one reviewer (HC). Participant quotes, categories, themes along with original authors discussions and conclusions were extracted, transcribed and coded onto NVivo 11 by one reviewer (HC or TG). A second reviewer (FA and TG or HC) cross-checked paper versions independently.

2.7 Data Synthesis and Interpretation

Meta-ethnography involves seven steps, the aim being to translate findings (metaphors, concepts and themes) from individual qualitative studies into new interpretations that transcend the original primary studies (Noblit & Hare, 1988). Following definition of the topic, search strategy, study selection and quality appraisal, the authors began by reading and re-reading the studies to identify key concepts. We started with studies identified as being high quality through our appraisal process and having higher number of citations. Then, one reviewer (HC or TG) coded text line-by-line and a second reviewer (FA and TG or HC) coded paper versions. We considered all data extracted, however greater emphasis was placed on participant quotes and primary data when beginning to compare studies. In the first stage of analysis, themes were descriptive. A process of constant comparison followed in which concepts were translated across studies (Tong et al, 2012). These concepts were re-applied to the primary data which enabled us to reach consensus about how they connected within the synthesis and enabled the development of ‘lines of argument’ (Finfgeld, 2003).

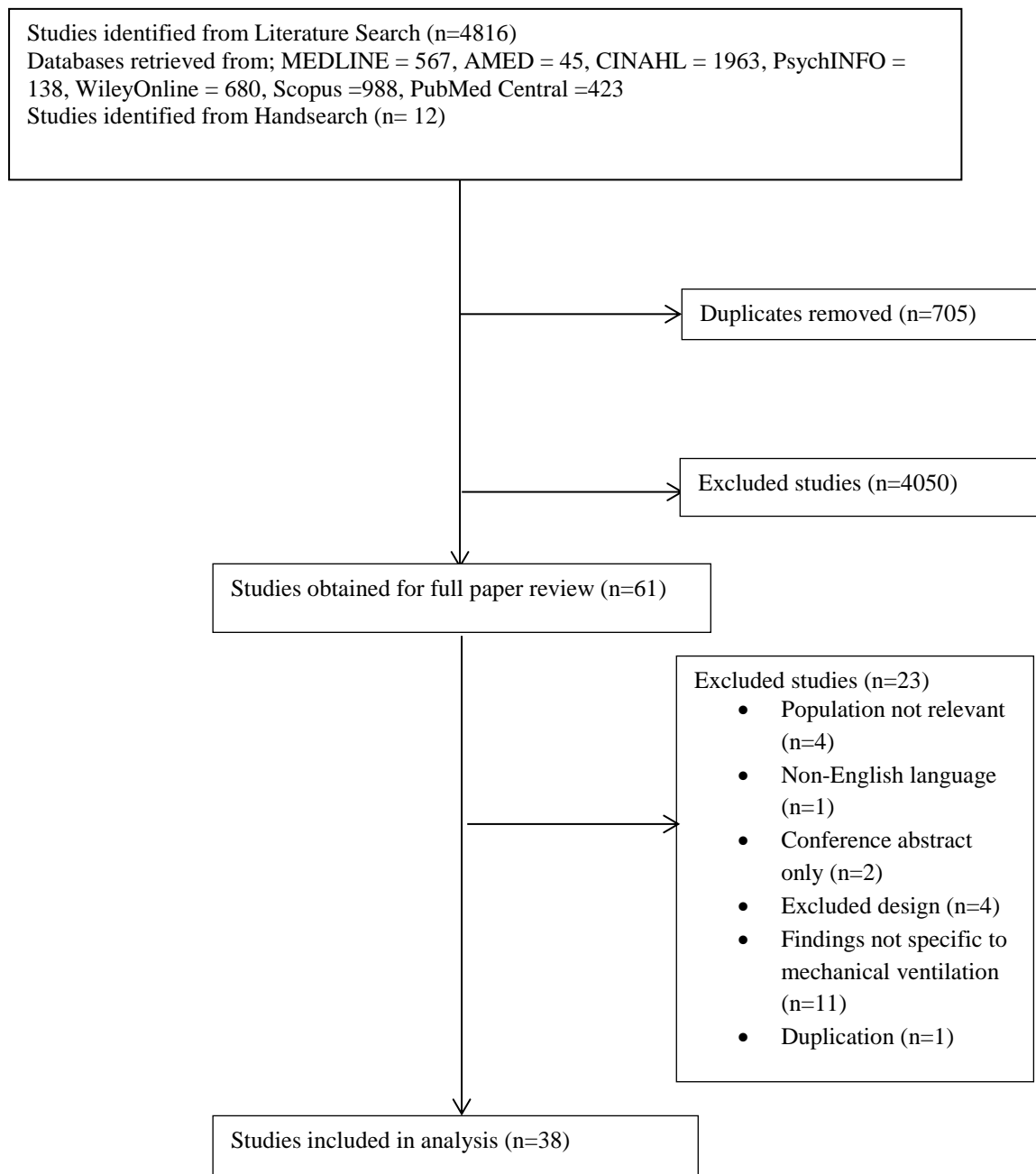
We adopted several approaches to support a rigorous data analysis process; a clear audit trail, the use of NVivo11 software to manage and retrieve the data and regular research team meetings to discuss the analytical process and findings. The team discussed their different professional viewpoints (a physiotherapist, a psychologist, and an adult nurse previously employed as a nurse consultant in Intensive Care) which supported a reflexive approach to the synthesis. The team could discuss their interpretations of data from their own frame of reference and ensure all aspects were considered, including data that refuted preliminary ideas, when synthesising the study findings.

A meta-ethnography is ideally suited to explain patients' views and develop new explanatory models and theories. In keeping with this methodological approach, we did not start with a theory but aimed to develop one. However, during the data analysis process the concept of the physical and psychological 'work' required by participants during mechanical ventilation in Intensive Care Units became apparent. This finding aligned with concepts described in the seminal Illness Trajectory Model developed by Corbin and Strauss to explain chronic illness 'work' (1985). We used the concepts of 'illness work' (work needed for diagnostic purposes or symptom control, e.g. taking medication), 'everyday life work' (work needed to take part in family daily life, i.e. to complete housework or social activities) and 'biographical work' (the reconstruction of their life or biography) described in this middle range explanatory nursing model as a 'lens' to assist us in developing our model. We applied the three lines of work theory conceptualised by Corbin and Strauss (1985) in an innovative way to help us to compare and contrast the 'work' required by patients receiving mechanical ventilation in Intensive Care Units compared to those self-managing chronic conditions in home setting.

3. Results

Figure 1 shows the details of the search which identified 4816 articles with 38 articles included in the final review. All relevant references of any identified published reviews were included prior to citation tracking from the electronic search and hand-searching.

Figure 1: Flowchart for study selection



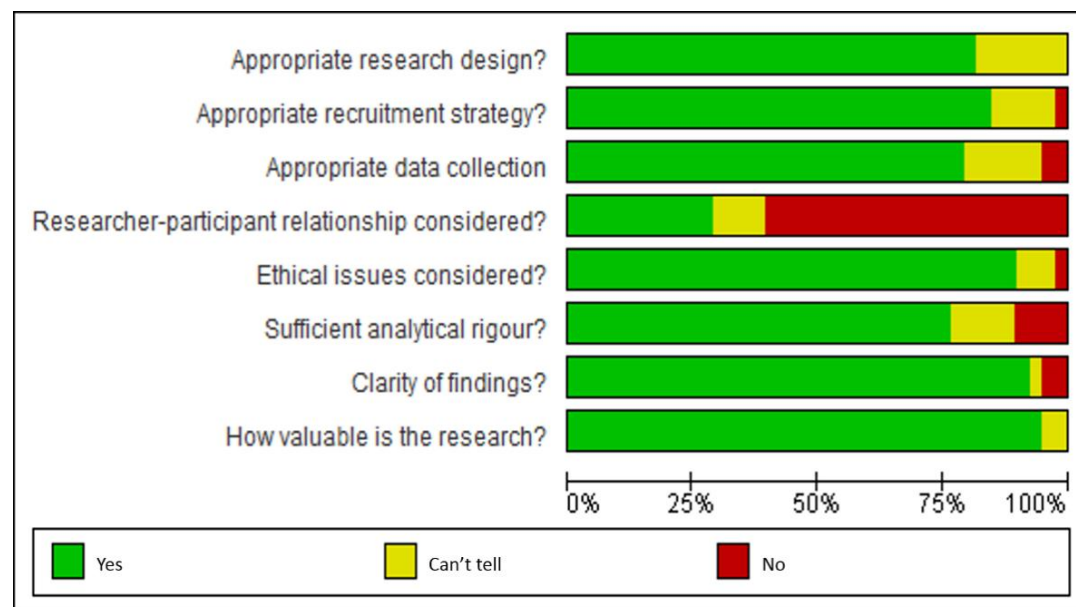
*inter-reliability between reviewers between reviewers for the selection process was good ($k=0.71$).

3.1 Quality appraisal

Figure 2 shows a summary of the results of the quality appraisal that was conducted using the CASP qualitative checklist (CASP, 2017). In general, the quality of the 38

included studies was rated as good. The most common limitation was the lack of reporting about the critical evaluation of the role of the researcher and how this might influence the research (n=27 studies). This lack of reflexivity could potentially influence the trustworthiness of the data analysis and interpretation. In 9 studies the procedures used to support the rigour of the data analysis processes were either unclear or not reported which could affect the robustness of findings. In 8 studies there was a lack of explanation about how the data collection techniques aligned with the research questions but this may have been a reporting issue rather than a methodological one as word limits often preclude lengthy explanations. The consistency in quality appraisal across reviewers was moderate ($k=0.46$). The quality appraisal of the individual studies is provided in a supplementary data.

Figure 2: Quality appraisal of the included studies



The quality appraisal of the included studies based on questions 3 to 10 in the CASP qualitative checklist [22]. Question 10 was modified from 'How valuable is the research?' to 'Was the research valuable?' to allow comparison. Equal weighting was given to each element.

3.2 Study Characteristics.

Table 2 shows a summary of the included studies. Four research teams described different interpretations of data from the same participants in two articles, namely Johnson et al (2006) and Johnson (2004); Logan & Jenny (1997) and Jenny & Logan (1996); Karlsson et al [2012a; 2012b]; Lof et al (2008; 2006). Both interpretations of the same participant data were included in the analysis as different aspects of the experience were reported and explored. The cohort of 38 international studies represented the views of 608 participants from Europe (n=19), North America (n=10), Australia (n=5), Asia (n=3), and South Africa (n=1). Participants received mechanical ventilation electively as part of pre-planned admission for high risk major surgery, trauma or other medical conditions. From the available data it was not possible to evaluate whether emergency or elective admission to Intensive Care Units affected participants' experiences. The most frequently used qualitative methodology was phenomenology (n=22) although other approaches were used such as grounded theory and ethnography, using participant interviews, focus groups and observations.

Table 2: Summary of included studies

Article	Country of study	Participant information	Reasons for Critical Illness	Data collection data recording and analysis	Theoretical approach	Key themes taken from the study
Alpers et al (2012)	Norway	N=6, Gender=3M 3F, Age Range=60-73	Infection, heart disease, renal failure, asthma, respiratory failure	Interviews, 3-6 months after discharge from hospital	Phenomenology	To have the support of next of kin; The wish to go on living; To be seen; Signs of progress
Arslanien-Engoren & Scott (2003)	US	N=7, Gender=1M 6F, Age Range=22-69	Gastro-intestinal bleed, Cerebral Vascular Accident, hypotension, trauma, Sciatica, Ileus	Semi-structured telephone interviews, 2 years from discharge	Phenomenology	Endures a traumatic experience; Relies on self-determination; Credits family support and devotion; Finds comfort through religion and prayer; Praises Health Care Professionals; Derives reassurance from angelic encounters
Chen et al (2009)	Taiwan	N=20, Gender=8M 12F, Age Range=42-86	Missing data	In depth interviews, within 72 hours of weaning	Phenomenology	Dealing with the unfamiliar contexts of the weaning programme; Experiencing various psychological responses and ambiguity of self-endurance; Being tortured by helplessness; Wondering whether to give up; Release from self-breathing
Claesson et al (2005)	Sweden	N=8, Gender=7M 1F, Age Range=32-81	Missing data	Interviews, 6-12 weeks after Intensive Care Unit discharge	Missing information	Real experiences; Imaginary experiences
Clukey et al (2014)	US	N=14, Gender=11M 3F, Age Range= missing data	Missing data,	Interviews, at bedside in hospital but discharged from Intensive Care Unit	Phenomenology	Lack of memory; Intubation as torture; Nurses' interventions
Donnelly & Wiechula (2006)	Australia	N=4, Gender= missing data, Age Range= missing data	Missing data	Non-structured interview, no detail of time	Phenomenology	Physical sensation; Psychological preparation; Trust and confidence; Essentialness of communication

Article	Country of study	Participant information	Reasons for Critical Illness	Data collection data recording and analysis	Theoretical approach	Key themes taken from the study
Engstrom et al (2013)	Sweden	N=8, Gender=4M 4F, Age Range=45-72	Major trauma, myocardial infarction, cardiac arrest, sepsis, deteriorating pulmonary disease, post-operatively	Interviews, six months after cessation of ventilation	Content analysis	Being delivered into the hands of others; That the unlikely was reality
Flinterud & Ambershed (2015)	Norway	N=11, Gender=8M 3F, Age Range=47-72	Missing data	Semi-structured interviews, 3-18 months since hospital discharge	Content Analysis	Experience of caring and understanding despite having uncomfortable feelings due to troublesome communication
Forbes (2007)	US	N=4, Gender=3M 1F, Age Range=55-75	Chronic obstructive pulmonary disease	Interview, no detail of time	Phenomenology	Sinking into blackness; Overwhelming loss of autonomy; Taking control; Becoming a person again; Redefining myself
Fowler (1997)	US	N=10, Gender=8M 2F, Age Range=31-65	Vascular surgery (coronary and carotid), motor vehicle accidents, post-operative with morbid obesity	Semi-structured interview, within 5 days of extubation	Descriptive	No themes discussed
Hafsteindottir (1996)	Iceland	N=8, Gender=4M 4F, Age range=18-68	Pneumonia, Coronary Artery Bypass Graft, respiratory failure, myocardial infarction, adenocarcinoma vateri, diverticulitis, trauma	Interviews, no details of time	Phenomenology	Impaired communication; Feelings of negative emotions; Feelings of tiredness and exhaustion; Feeling the need for communication; The feelings of awareness and acceptance; Feeling the support from relatives; Problems with communication methods; Impaired recollections; Feeling of suffocation; Experience of hallucinations, nightmares and confusion
Holm & Dreyer (2017)	Denmark	N=4, Gender=0M 4F, Age Range=61-86	Pleural effusion, multi-trauma, pneumonia	Semi-structured interviews, 1-2 days after extubation	Phenomenology	The tube in the throat; To be conscious but feeling doped; When passing of time is dragging on

Article	Country of study	Participant information	Reasons for Critical Illness	Data collection data recording and analysis	Theoretical approach	Key themes taken from the study
Jablonski (1994)	US	N=12, Gender=5M 7F, Age Range=24-73	Surgery, respiratory distress, cardiac arrest, Guillain Barre, ruptured cerebral aneurysm	Interviews, 2-108 months from ventilation	Phenomenology	Pre-ventilator event; Realisation of respirator; Proximity of death; Patients' responses to the mechanical ventilation; Responses to endotracheal tube or tracheostomy; Physical care and therapies; Effect of mechanical ventilation on senses, Communication; Role of significant others; mechanical ventilation mishaps; Interactions between patients and Health Care Professionals; The process of weaning; Extubation and respirator removal; After effects of mechanical ventilation; Recommendations from patients
Jenny & Logan (1996)	Canada	N=20, Gender= missing data, Age Range=19-83	Mix of surgical and medical patients	Interview, 5 days from transfer from Intensive Care Unit	Grounded theory	Physical discomfort; Nurse caring; Altered self; Patient work
Johansson & Fjellman-Wiklund (2005)	Sweden	N=7, Gender=4M 3F, Age Range=48-68	Planned and acute surgery, or requiring intensive therapy and/or support	Interviews, 10 days to 6 years after Intensive Care Unit discharge	Grounded theory	Altered body functions and difficulty to control the body; Changed appearance; Existential thoughts; Not at one with the body; Lack of trust in the body/themselves; Not in contact with reality; A feeling of being restrained
Johnson et al (2006)	Australia	N=9, Gender=6M 3F, Age Range=21-69	Mix of surgical and medical patients	Unstructured interviews, 2 weeks to 2 months from hospital discharge	Phenomenology	Being thrown into an uneveryday world; Existing in an uneveryday world; Reclaiming the everyday world; Reframing the experience
Johnson (2004)	Australia	N=9, Gender=6M 3F, Age Range=21-69	Mix of surgical and medical patients	Unstructured interviews, no details of time	Phenomenology	Being thrown into an uneveryday world; Existing in an uneveryday world; Reclaiming the everyday world; Reframing the experience
Jordan et al (2002)	South Africa	N=5, Gender=2M 4F, Age Range=22-54	Missing data	Interview, 12-48 hours after Intensive Care Unit discharge	Phenomenology	Experiences of patient related to the process of ventilation; The patients experience of the environment while connected to the mechanical ventilation

Article	Country of study	Participant information	Reasons for Critical Illness	Data collection data recording and analysis	Theoretical approach	Key themes taken from the study
Karlsson et al (2012a)	Sweden	N=12, Gender=9M 3F, Age Range=23-88	Epiglottitis, Cerebral Vascular Accident, Myelitis, difficult intubation, laryngeal Cancer, trauma, carotid surgery, airways obstruction, sepsis with pneumonia	Interview, one week after Intensive Care Unit discharge	Phenomenology	Experiencing a sense of control; Being viewed as a participant and companion; Yearning for independence
Karlsson et al (2012b)	Sweden	N=14, Gender=10M 4F, Age Range=23-88	Epiglottitis, Cerebral Vascular Accident, myelitis, difficult intubation, laryngeal Cancer, trauma, carotid surgery, airways obstruction, Chronic obstructive pulmonary disease, Myasthenia gravis, sepsis with pneumonia	Video-taped interview during mechanical ventilation	Phenomenology	Tube and tracheotomy causes pain, Discomfort and breathing difficulties; Suction procedure caused panic but also relief; The tube took away the voice and made communication strange; The presence of relatives and nurses evoked feelings of security and well-being; Hope and longing to be healthy and return to a normal life; Not being able to sleep and rest
Karlsson & Forsberg (2008)	Sweden	N=8, Gender=4M 4F, Age Range=21-81	Epiglottitis, sepsis, Guillain Barre, post-operatively	Interview, no details of time	Phenomenology	Memories; Mastering one's situation; A renewed me; Confirmation
Locsin & Kongsuwan (2013)	Thailand	N=10, Gender=7M 3F, Age Range=22-76	Coronary Artery Bypass Graft, coronary balloon dilation, Lupus, Acute Respiratory Distress Syndrome, Gall bladder rupture	Interview, no details of time	Phenomenology	Lived body: living suffering; Lived relation: harmonizing living; Lived Space: being in trust and security; Lived time: transitioning to a better life

Article	Country of study	Participant information	Reasons for Critical Illness	Data collection data recording and analysis	Theoretical approach	Key themes taken from the study
			with sepsis, Renal disease, sepsis			
Lof et al (2008)	Sweden	N=9, Gender=6M 3F, Age Range=42-77	Pneumonia, Multi-trauma, Coronary Artery Bypass Graft, Guillain Barre, Myocardial infarction, Sepsis,	Interview at 3 and 12 months after Intensive Care Unit discharge	Content analysis	Chaotic and incomprehensible or in a memory gap until waking up in Intensive Care; Being trapped in a fragmented world of turmoil, dread, uncertainty and facing imminent death; Fright and bewilderment but also security or period of no recall/and waking up after a long sleep; Striving for recovery and making the situation comprehensible
Lof et al (2006)	Sweden	N=9, Gender=6M 3F, Age Range=42-77	Pneumonia, Multi-trauma, Coronary Artery Bypass Graft, Guillain Barre, Myocardial infarction, Sepsis,	Interview, at 3 and 12 months after Intensive Care Unit discharge	Content analysis	Recall, non-recall and fragmentary memories of factual events and Recall of unreal experiences
Logan & Jenny (1997)	Canada	N=20, Gender=9M 11F, Age Range=19-83	Mix of surgical and medical patients	Interview, 6-13 days from Intensive Care Unit discharge	Grounded theory	Sense making; Enduring; Preserving self; Controlling responses
Patak et al (2004)	US	N=29, Gender=19M 10F, Mean age=55 (SD17.27)	Valvular disorders, cardiomyopathy, Coronary Artery Disease, Congenital, aneurysm, organ transplant, surgical resection, pulmonary, trauma, renal	Interview, within 72 hours of extubation	Content analysis	Health care providers can promote communication; Characteristics and attributes of the health care provider directly impact the patients ability to communicate; Characteristics and attributes of the health care provider can discourage and impede patient communication
Pattison & Watson (2009)	UK	N=1, Gender=1F, Age=63	Breast Cancer, chest infection,	Unstructured interview,	Case study	Dysfunctional ventilator weaning response; A Eureka moment; Anxiety; Impaired verbal

Article	Country of study	Participant information	Reasons for Critical Illness	Data collection data recording and analysis	Theoretical approach	Key themes taken from the study
			kyphosis, myalgic encephalomyelitis	following discharge from hospital ward		communication; Influence of reassurance and presence on weaning
Samuelson (2011)	Sweden	N=250, Gender=128M 122F, Mean age=63	Medical reason, post-operative, multiple trauma	Interview, 3-5 days following Intensive Care Unit discharge	Content analysis	Physical distress and relief of physical distress; Emotional distress and wellbeing; Perceptual distress and wellbeing; Environmental distress and comfort; Stress inducing care and caring service
Schou & Egerod (2008)	Denmark	N=15, Gender=8M 2F, Age Range=35-84	Post-Coronary Artery Bypass Graft	Semi-structured interview, 2-5 months from hospital discharge	Phenomenology	General phenomena; Psychological phenomena; Existential phenomena
Sheen & Oates (2005)	Australia	N=5, Gender=4M 1F, Age Range=missing data	Missing data	Interview, 6-12 months from hospital discharge	Phenomenology	Utter helplessness; Cognition; Succour
Sherlock et al (2009)	UK	N=8, Gender=5M 3F, Age Range=19-76	Cardiac surgery, head and neck cancer, neurological condition, respiratory failure	Semi-structured interview, 0-32 days from de-cannulation of tracheostomy	Pilot qualitative study	Physical sensations; Understanding; Information; Experiences after removal of tracheostomy tube
Stayt et al (2015)	UK	N=19, Gender=8M 11F, Mean age 57.5 (SD 12.4)	Elective post-operatively, sepsis, pneumonia, trauma	Interview, 3-7 months from Intensive Care Unit discharge	Phenomenology	Inseparability of Technology and Care; Getting on with it; Getting over it
Storli et al (2008)	Norway	N=10, Gender=4M 6F, Age Range=28-70	Trauma, extensive surgery, life-threatening infections	Interviews, no details of time	Phenomenology	Looking back; The journey; Ten years later
Tate et al (2012)	US	N=30, Gender=missing data,	Missing data	Observation and debrief interview, no details of time	Ethnography	Prevalence of anxiety & agitation events; Interaction as the core process; Patient appraisal; Patient responses; Clinician assessment; Managing anxiety and agitation

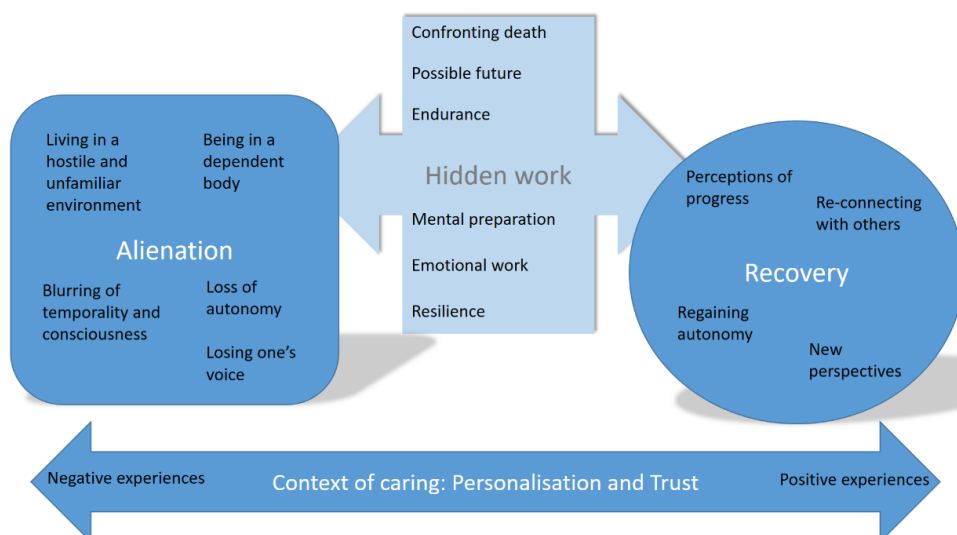
Article	Country of study	Participant information	Reasons for Critical Illness	Data collection data recording and analysis	Theoretical approach	Key themes taken from the study
		Age Range=missing data				
Tembo et al (2015)	Australia	N=12, Gender=7M 5F, Age Range=20-76	Cardiac event, haemothorax, Chest infection, metabolic acidosis, Coronary Artery Bypass Graft, aortic bypass, cardiac arrest, traumatic chest injury, Status epilepticus, surgery, road traffic accident	Interviews, two weeks after Intensive Care Unit discharge	Phenomenology	Being imprisoned; Being voiceless; Being trapped; Waiting for the familiar and reliable voice
Todres et al (2000)	UK	N=1, Gender=F, Age=missing data	Disseminated intravascular coagulation	Interview, no details of time	Phenomenology	Coming to terms with people and things that know better than me how I am; The dilemmas of others knowing how I am but not who I am; Entering a twilight world; The frightening nature of breathing problems; I did not know what to do with myself; The frustration of not being understood; Ambivalent feelings during the weaning process; The importance of having an advocate; Sleep and sedation; Fear and thoughts of death
Wang et al (2009)	China	N=11, Gender=8M 3F, Age Range=33-78	Missing data	Interviews, no details of time	Phenomenology	Being in an unconventional environment; Physical suffering; Psychological suffering; Self-encouragement; Self-reflection
Wunderlich et al (1999)	US	N=19, Gender=7M 12F, Age Range=missing data	Missing data	Structured interview, no details of time	Exploratory retrospective design	Determine levels of stress and uncertainty; Determine helpfulness of information; Determine the effect of other variables; Explore patients' perceptions;

In all studies, mechanical ventilation was experienced in an Intensive Care Unit (ICU). Abbreviations: M – Male, F – Female, N - number

3.3 Results of synthesis

Figure 3 shows the product of the synthesis which is a patient-centred trajectory model of mechanical ventilation in the Intensive Care Unit. The term ‘trajectory’ is used to describe the course of a critical illness in Intensive Care Units which is represented by three overlapping stages that includes a period of mechanical ventilation and the weaning process. The characteristics of the ‘journey’ are somewhat enforced by the acuity of the clinical condition as patients do not have the option to ‘step off’. We include the related ‘work’ done by patients to endure mechanical ventilation and the effect on relationships with family members and health professionals. The trajectory began when consciousness was regained, for long enough to enable the patient to begin to become aware of the Intensive Care Unit environment and the sensations associated with mechanical ventilation, to the realisation that their clinical condition must be improving as they were weaned from mechanical ventilation and could begin to breathe unaided.

Figure 3: A patient-centred trajectory model of the experience of mechanical ventilation survivors in Intensive Care Unit settings



The model shows the synthesis of Intensive Care Unit survivors' accounts of the experiences and responses to mechanical ventilation. Accounts described participants drifting in and out of consciousness and becoming aware of an unfamiliar environment. They had little, or no control, over their body and could not speak leading to feelings of alienation. As they had lost physical control over normal bodily functions greater emphasis was given to cognitive and emotional 'work'. The 'hidden work' was part of coping with mechanical ventilation and was 'invisible' to health professionals but was part of the transition towards either recovery or relapse. The recovery trajectory for Intensive Care Unit survivors treated with mechanical ventilation can be of varying speeds and reversible, and is affected positively or negatively by the context of care which involves personalisation and trust.

To support the robustness of our data analysis we have provided a clear audit trail in the supplementary data which indicates which themes and subthemes were evident in each of the studies included in the synthesis and the primary data (patient quotes and author concepts) that informed the development of themes and subthemes.

3.3.1 Alienation (Stage 1)

The experience of regaining consciousness and becoming aware of undergoing mechanical ventilation was conceptualised as “alienation”. This is because participants reported experiences of waking up in a strange body, in a strange place with no control over voluntary bodily movements and physical functions leading to feelings of a distorted reality. This stage comprised five sub-themes shown in Figure 3.

3.3.1.1 Living in a hostile and unfamiliar environment (Sub-theme 1a)

As participants drifted in and out of consciousness they became aware of being thrust into *living in a hostile and unfamiliar environment*. It was an environment that was unlike any other previously experienced.

A young participant said she felt like Darth Vader, because all she could hear was the ventilator, and another noted, "Sometimes it was like you were a stranger from another planet" (Logan & Jenny, 1997)

“...I found I have come into another place...I did not know what happened outside...that was a strange place which was like being in another world.”

(Wang et al, 2009)

An environment of tubes and technology against unfamiliar noises and sensations was confronting and threatening;

“I woke up and the curtains were drawn between our two beds ... it was a blood-curdling type screaming ... but luckily my nurse was there ... and I can remember she touched me, held my hand and said not to worry (Todres et al, 2000)

The presence and care from health professionals helped to alleviate the feelings of being in a hostile environment;

“I felt attached to this unit as if it was another home of mine. They helped in every way ... the doctor, I could recall when I started to feel tight in my chest, the nurse walked to me and checked on me very often to observe my condition.” (Locsin & Kongsuwan, 2013)

The presence of health professionals at the bedside helped to create a sense of their ‘vigilance’ within the context of caring. This helped participants to feel more secure and safe in their environment.

3.3.1.2 Being in a dependent body (Sub-theme 1b)

The reliance on technology and others to survive created the feeling of *being in a dependent body*. It heightened the dehumanising element of the experience.

“It was uncomfortable when I was dependent on the mechanical technology. It was that I was not being my own self. It was like I had other things helping me. I couldn’t do anything by myself at all” (Locsin & Kongsuwan, 2013)

Participants were not able to rely on their bodies for survival and needed the technology and carers to continue living. The technology necessitated uncomfortable procedures and tubes.

“You know, if you need it, and it does a good job and it helps you, I suppose the misery is worth it. But I would offer this as a good torture for Guantanamo.” (Clukey et al, 2014)

For some participants this experience was likened to torture but the necessity of treatment was perceived when their body was dysfunctional.

“The ventilator was a saviour at times” (Sheen & Oates, 2005)

Participants were dependent on others and technology to work for them when their bodies became untrustworthy and unreliable.

3.3.1.3 Blurring of temporality and consciousness (Subtheme 1c)

The environment had no discernible night and day and no recognisable external cues. When combined with dreams, nightmares and the effects of medications a *blurring of temporality and consciousness* occurred.

“Everything was very fuzzy and I can only remember a few bits. It was all sort of diffuse, even though I had not been given any anaesthetics or medicines.” (Löff et al, 2006)

The Intensive Care Unit environment and medications made it difficult for participants to track the passage of time. It created a distorted experience that was difficult to unravel meanings from.

“And that is probably because you are so doped... I mean, even though you are conscious, you are still doped”. (Holm & Dreyer, 2017)

Losing touch with reality was a recurrent concept within the Alienation stage.

3.3.1.4 Loss of autonomy (Subtheme 1d)

The inability to take control of normal physical functions, even breathing, led to a reported *loss of autonomy*. It created a feeling of helplessness where participants had no agency in their world.

“I was like a vegetable, without being able to do anything by myself. It made me feel very defenceless and helpless.” (Wunderlich et al, 1999)

“...it’s just the fact that once that (intubation and mechanical ventilation) happens, you’ve got no say” (Todres et al, 2000)

The inability to control any physical functioning or alleviate uncomfortable physical sensations was understandably distressing for participants.

“And then they drank Coca Cola and I could hear the fizz. I was very thirsty and my mouth was ever so dry but nobody offered me anything and nobody spoke to me either” (Karlsson & Fosberg, 2008)

The loss of autonomy led some participants to feel very isolated which was aggravated by the loss of communication described in the next subtheme.

3.3.1.5 Losing one’s voice (Subtheme 1e)

The loss of control combined with *losing one’s voice* created strong feelings of depersonalisation.

“When I most needed to communicate I couldn’t speak, and I couldn’t really make myself understood.” (Patak et al, 2004)

The inability to communicate with the outside world made participants feel very isolated and alone in their thoughts.

One subject described her experiences as similar to being in “one of those dreams where you want to scream but can’t”. (Samuelson, 2011)

It made the experience like a nightmare and it was difficult for participants to gain comfort from others due to their physical incapacity and inability to communicate.

3.3.2 Hidden work (Stage 2)

Participants were forced to spend their conscious time in an internal world that increased the focus upon their own cognitions and emotions mainly because they were alienated and unable to function or communicate with others in a familiar way. They needed to engage in cognitive and emotional 'work' to enable them to cope with their changed situation and focus on how to survive. This 'work' was largely hidden from the outside world. Participants engaged in 'illness work' although this was mainly restricted to internal ways to manage symptoms, and 'biographical work'.

'Biographical work' involved a realisation of the near-death experience and consideration of possible outcomes to decide on their motivation to work. This tallies with the theory from Corbin & Strauss (1985), as motivation during the chronic illness trajectory depended on the trajectory itself, biographical schemes, hope, and commitment. The stage comprised of six sub-themes.

3.3.2.1 Confronting death (Subtheme 2a)

As part of coping, participants described their thoughts about *confronting death*.

John described his encounter with a black shadow, which he termed ‘the visitor’. He experienced this as being close to, or confronted by death and “going over to the other side”. (Logan & Jenny, 1997)

Death was a possibility, and participants reflected on it. Part of this 'biographical

work’ was exploring their spirituality and religious beliefs.

“So I didn’t think I’d get through the operation... I was too weak, and I was tired of it all.” (Löf et al, 2008)

“The whole time I just prayed that it must be over soon - that I could make it and not die.” (Jordan et al, 2002)

It seemed that this was part of ‘making sense’ of their critical illness and possible trajectory. This allowed them to consider their commitment to work for survival or death.

“I tried to take my own life as I lay there, disconnect the respirator, escape from this life altogether” (Karlsson & Fosberg, 2008)

Death was something they needed to acknowledge before considering other possible outcomes.

3.3.2.2 Possible futures (Subtheme 2b)

Participants described spending time thinking whilst ventilated in Intensive Care about what *possible futures* might hold for them and their loved ones.

“I didn’t want other persons to be burdened because of me. I wanted to die if I could; that was what I thought ... didn’t want anyone to help” (Stayt et al, 2015)

“I think it’s that feeling that you have someone to live for, in short! Someone who sits there, whom you know loves you, who really wants you to survive!” (Storli et al, 2008)

This ‘biographical work’ of considering the illness trajectory alongside what their wishes were for the future allowed a decision to be made about their motivation to

survive. As part of this they also considered what their survival might mean and how they would work towards enduring the experience.

3.3.2.3 Endurance (Subtheme 2c)

Focusing on accepting death or striving for survival influenced the level of *endurance* participants had. This is the beginning of participants undertaking ‘illness work’ where they are attempting to manage their own symptoms and mentally working towards survival or not.

“You’re breathing for your life, I was exhausted” (Karlsson et al, 2012a)

Those who lacked the motivation to actively endure mechanical ventilation and to strive for survival, became passive in their endurance.

Participant 3 described this as ‘at their mercy’. Other participants recalled ‘giving in to it’ (Participant 5) and ‘letting them get on with it’ (Participant 16), (Wunderlich et al, 1999)

These differing accounts highlight the decisions made during ‘biographical work’ as to their motivation to strive for ‘illness work’ in the Intensive Care Unit environment. Some participants used active processes to find ways to survive whilst others become more passive and resigned to accepting their circumstances.

3.3.2.4 Mental preparation (Subtheme 2d)

Those who chose active approaches described using *mental preparation* whilst in Intensive Care Unit as a technique to prime themselves for the discomfort of care and associated procedures.

“I think the best way is once you’ve had it done once and you know you’ve gotta have it done a second time is just to grin and bear it, really attack it

mentally otherwise it'd just bloody drive you crazy I think" (Claesson et al 2005)

Information from health professionals was needed to facilitate this work.

"Dr. X said he would be turning off the machine in several days. I was not sure what I needed to do to prepare." (Chen et al, 2009)

This shows the scope of the hidden cognitive 'illness work' that participants do whilst they are mechanically ventilated.

3.3.2.5 Emotional work (Subtheme 2e)

Hope is an important factor that affects motivation for work, and this will be eroded by negative emotions. The experience of mechanical ventilation and associated procedures aroused feelings such as fear, anxiety and loneliness.

"It was unpleasant the whole time, at least what I remember. Then afterwards, I don't know, but I felt such anxiety, I nearly panicked." (Wang et al, 2009)

Being unable to communicate caused the emotions to be all-encompassing and participants needed to work to cope with them.

"The worst was being left on my own, not being able to speak and being concerned that you were alone. No-one to help you". (Sheen & Oates, 2005)

Those engaged with their surrounding allowed hope and were able to work both within the illness and everyday lines of work as observed during an observational study.

Cluster 4 patients were the most interactive; they were able to communicate wants and needs effectively and appropriately, most often by nonvocal methods. They reacted more calmly to tactile or verbal stimuli, and were more cooperative with care. (Tate et al, 2012)

The emotions that participants reported had a significant impact on their well-being whilst in ICU.

3.3.2.6 Resilience (Subtheme 2f)

Resilience was needed to combat these emotions and to continue to be motivated towards work, participants needed to work to cope with them. Maintaining hope or a positive outlook was described as being helpful.

“I was an optimist, I thought I recovered more quickly than others.” (Wang et al, 2009)

One person attributed her success in being liberated from PMV [Prolonged Mechanical Ventilation] to her self-proclaimed determination to “get off of it. Ya know, I gotta be able to talk to my family and communicate; [to] try to be as normal as possible.” (Arslanian-Engoren & Scott, 2003)

Having resilience was needed to cope with the negative emotions aroused whilst ventilated and facilitated motivation to work towards recovery.

3.3.3 Recovery (Stage 3)

Perceptions of recovery as indicators of a transition towards eventually being able to return home was immensely important to participants. This movement entailed becoming a person again with control over their bodies, actions and environment. Alongside ‘illness’ and ‘biographical work’, this stage also involved ‘everyday life work’ as participants sought re-entry into their daily lives and routines needed for living. Four sub-themes comprised this stage.

3.3.3.1 Perceptions of progress (Subtheme 3a)

Perceptions of progress were important to maintain hope that recovery was possible and sustain the motivation to work. Often participants were not sure if their condition was getting better or worse so they 'looked' for signs that might indicate they were recovering.

“So as each drip disappeared and they took off the things from my leg I knew it meant that I could do more for myself.” (Stayt et al, 2015)

A lack of positive signs aroused negative emotions.

“I have really tried to adapt to the weaning process, but there has only been a little improvement. It gets me down. What can I do?” (Chen et al, 2009)

The presence of supportive staff helped to alleviate negative emotions and maintain the perception of progress.

“When I had these tears of frustration I found everyone really wonderful, you know: ‘we understand your tears of frustration’. And you know I would get reassurance and it would pass quite quickly.” (Pattison & Watson, 2009)

This shows how important external signs of recovery are to Intensive Care Unit patients and how they looked to these signs to internally monitor their improvements. It was vital to allow participants to consider their illness trajectory and biographical schemes as part of their ‘biographical work’.

3.3.3.2 Re-connecting with others (Subtheme 3b)

The journey to recovery involved *re-connecting with others*. Re-connecting with others brought participants closer to feeling human again. It involved the commencement of ‘everyday life work’ following their critical illness as they were able to engage with loved ones again.

Participants reported that when they were able to re-engage with others, they felt that they were making positive progress towards recovery and moving out of the Cardiac ICU [Intensive Care Unit]. (Johnson, 2004)

It allowed participants to communicate their needs and gain both emotional and physical support in their recovery.

After a while the staff learned to understand what the participants wanted to say and they found their own ways to attract attention, e.g. by using the saturation probe on their finger to knock on the side of the bed when they were thirsty. (Engström et al, 2013)

The connection to others allowed participants to re-enter aspects of their everyday life.

3.3.3.3 Regaining autonomy (Subtheme 3c)

Gaining control in the decisions over treatment and the care received was an important step towards away from alienation. It is part of ‘everyday life work’ to make autonomous decisions about their life, and regaining this autonomy allowed participants to feel empowered.

Participants told of the many measures they used whilst on the mechanical ventilator to wrest back, or gain some control, over their treatments. (Johnson, 2004)

However, as time passed, the participants gained control over their body, thereby enabling them to use aids, such as pointing at picture boards and writing with pen and paper. (Flinterud & Andershed, 2015)

The autonomy allowed participants to make their wishes clear and feel less helpless when receiving care by taking part in ‘everyday life work’.

3.3.3.4 New perspectives (Subtheme 3d)

Following survival, participants reflected on what had happened to them and tried to make sense of their experiences to create a new perspective. It involved ‘biographical work’ to reconstruct their thought about their lives going forward.

“At the moment, the most important thing is to live a happy life.” (Locsin & Kongsuwan, 2013)

A full recovery was not possible for every participant as negative emotions remained making it difficult to find a new perspective.

One of the informants who still goes to regular check-ups at the hospital tells of days of dread at the thought of going to the hospital. “I always get a tightness in my chest when the taxi approaches the hospital.” (Storli et al, 2008)

If negative emotions remained, some used acceptance as a way of coping with them.

“If someone or something touches my throat, everything gets constricted in me! (.) You get a feeling that you might die! It is that feeling that comes back as well. And the feeling of suffocation, it really stays with you. I don’t think, in a way, that I will ever be rid of it. But now I can live with it.” Storli et al, 2008)

This shows the impact of the Intensive Care Unit experiences on psychological well-being in the long-term.

3.3.4 Context of caring

Personalisation and trust were interlinked in the context of care. The personalisation of care signalled that the health professional recognised the participant as an

individual and a human being. Participants trusted health professionals who cared for them in a way that made them feel like a person rather than an object. In this way personalisation of care and trust were inextricably linked and vital for participants receiving mechanical ventilation.

3.3.4.1 Personalisation

Personalisation was two-fold. Firstly, participants appreciated being seen as a human and deserving of basic rights. Secondly, they valued being seen as a unique person with their own personality. The presence of loved ones during their stay was important as it was perceived to make their uniqueness more visible to health professionals and provided an important link to their previous life. The perception of being involved in their care in some way was important to participants.

“They don’t ask me, as a patient, how I really feel and how I can contribute to my own care, and that’s very frustrating” (Jablonski, 1994)

“But they spoke to me, all of them. I understood that, and it was just fantastic. But I recall that she [the nurse] was also very good at holding hands and using touch. And I found that very comforting” (Flinterud & Andershed, 2015)

Family members or health care professionals who cared for them as a person, understood their individual needs and supported them.

“What she did was to come. That was the thing that was important. We talked about common things and... we also talked about the fact that I didn’t want visitors. If somebody wanted to visit me, just a few should be allowed.”
(Alpers et al, 2012)

“I knew that Dad could see what I wanted... so I just needed to point or start writing a word and he understood...” (Karlsson et al, 2012a)

The provision or non-provision of personalised care was perceived to positively or negatively influence participants' recovery. It supported 'everyday life' and 'biographical work' by nurturing supporting hope and re-entry into make everyday life decisions. Family members and health care professionals who offered such care were seen as a lifeline which connected them to the human they had been before becoming alienated.

3.3.4.2 Trust

Health professionals could instil trust by being vigilant in their care and attention or dispel trust by not being so. This was vital for participants because they were unable to complete their own 'illness work' independently and required others to complete this for them.

"It is very important, to have someone you care for and trust by your side.

People need to understand that one has very much need for that. Especially, when one is lying like this and can't move at all." (Hafsteindóttir, 1996)

"My thoughts weren't their thoughts. It was maddening. You never got any help. They'd walk out and they played this little game where I put on the light and they'd shut it. I'd put on the light and they shut it." (Patak et al, 2004)

Trust could be 'active' as participants recognised the expertise and vigilance of health professionals or 'passive' as they recognised they had no choice but to trust because of being in a completely vulnerable state.

One patient remarked, "Building trust with the doctors and nurses is very important. If you think they are not doing their job...this is not good." (Logan & Jenny, 1997)

Being able to trust others when vulnerable within the Intensive Care Unit was vital for the emotional wellbeing of participants.

4. Discussion

To improve care processes and provide high quality person-centred care it is important to understand patients' experiences. A recent study highlighted the importance of using the experiences of patients to develop patient-centred nursing practice (Laevkner et al, 2017). In the largest and most comprehensive body of qualitative research synthesised to date about participants' experiences of mechanical ventilation in Intensive Care, we present a patient-centred trajectory model. The model is comprised of three overlapping stages; 'alienation', 'hidden work' and 'recovery' with a fourth concept that describes the context of caring containing two themes 'personalisation' and 'trust'. The concepts from theory developed by Corbin and Strauss (1985) detailing three lines of chronic illness work were compared and contrasted with our final model. To our knowledge no study to date has comprehensively applied the concept of 'work' in an Intensive Care Unit setting and identified its components in the way we have.

In our synthesis, 'alienation' describes the first stage of the participant experience in which snatches of consciousness are regained. The participant becomes aware of the sensations of mechanical ventilation within an unfamiliar and hostile environment. This unpleasant experience is aggravated by physical and sensory limitations. Our interpretation differs from others as we have combined the themes of alienation and depersonalisation described in other studies (Sheen & Oates, 2005; Logan & Jenny, 1997) and elaborated on the key factors that contribute to 'alienation'. Our

interpretation expands upon the themes described in an earlier synthesis concerning the dehumanising effect of the loss of control when non-vocal (Carroll, 2004), by putting this in the context of the Intensive Care Unit environment during a time when reality is affected by altering consciousness.

Mechanical ventilation is a lifesaving intervention but with it comes a significant treatment burden for the patient and their family. The temporary loss of autonomy is caused by being in a dependent body that does not fully respond to internal commands aggravated by being unable to speak. The blurring of time and falling in and out of consciousness contributes to the sense of being in a hostile and unfamiliar environment. In this context the concept of ‘everyday life work’ described by Corbin and Strauss (1985) is unachievable and irrelevant as the participant can no longer participate in any of the familiar activities that occur in the home environment. In contrast the concept of ‘illness-related work’ is relevant as the participant must tolerate a range of unfamiliar and uncomfortable interventions such as the sensation of a machine forcing air into their lungs and feeling of suffocation that occur with endotracheal suction. The participant has to rely on technology and others to ‘do’ the ‘illness-related work’ for them which adds to their feelings of being helpless and vulnerable. The concept of ‘biographical work’ is also relevant in this stage as participants start to become aware of their situation and attribute meaning to their ‘unreal’ experiences.

The second stage of our synthesis was conceptualised as ‘hidden work’. ‘Hidden work’ involves the physical and psychological activity required to cope with mechanical ventilation that is largely invisible to health professionals and family. One

study conducted in an Intensive Care Unit setting did identify ‘work’ as being required of patients but this was limited to the process of weaning (Jenny & Logan, 1996) and did not reflect the ‘work’ required throughout the process of mechanical ventilation. Importantly, this is not a passive process as it may appear to others but involves strenuous effort and energy from the participants. The ‘work’ completed by participants involved both cognitive and physical ‘illness work’ in which participants prepared themselves emotionally and physically for the unpleasant mechanical ventilation treatment burden. The ‘biographical work’ involved the building of motivation to ‘work’ towards recovery. In this way some participants were passive in receiving Intensive Care Unit care whilst others were more active with a strong motivation to regain control.

The ‘recovery’ stage was a reinterpretation of themes described in primary studies (Forbes, 2007; Johnson et al, 2006; Johnson, 2004; Logan & Jenny, 1997) and data describing a process of reconnection with others and the discovery of a ‘new’ normal. This is a new stage not previously identified in earlier syntheses (Baumgarten & Poulsen 2014; Carroll, 2004). In our synthesis the perception of progress is seen from the patients’ perspective for the first time and is more than simply physiological improvement alone. In practice this means the experience of recovery for participants is only improved if the participant perceives progress and movement towards recovery and going home. In this stage, participants began to strive towards ‘everyday life work’ and connecting with others. Participants gained more control in completing their own ‘illness work’ which allowed them to see their recovery. ‘Biographical work’ and finding new perspectives and meaning from the experience was not consistent in all participants. Some were able to move in a positive way and

find new meanings to life, whereas others still experienced negative emotions. From this review, it is unclear why participants dealt with the experience differently.

Finally, the context of care from a participants' perspective, provides an important background for the stages presented in our synthesis. Primary studies in our synthesis identified the importance of 'personalisation' in care and 'trust' in others which could be a positive or negative influence and are therefore of paramount importance to the participants' recovery and care experience. From this synthesis, we can conclude that 'trust' in health professionals and the 'personalisation' of care constitute key elements of patient-centred care from the patient's perspective.

The interpretations from this synthesis enhance and further elaborate the findings of previous reviews and syntheses (Baumgarten & Poulsen 2014; Carroll, 2004) and the development of a model of patient-centred care in Intensive Care settings (Jakimowicz & Perry, 2015). Individualised care and a caring presence were identified as important to participants in facilitating communication (Baumgarten & Poulsen 2014; Carroll, 2004) which are similar to the themes of 'personalisation' and 'trust' in our synthesis. However, our synthesis goes further and identifies the importance of 'personalisation' and 'trust' throughout all elements of the mechanical ventilation patients' care and explains how it affects participants' 'work' through the trajectory.

Our synthesis adds a comprehensive understanding of the patient experience of mechanical ventilation for the first time. These findings can strengthen the patients' 'voice' in the recently published framework designed to guide patient-centred care in

Intensive Care settings (Jakimowicz & Perry, 2015). We have identified new concepts that add to the understanding of patient-centred care for patients treated with mechanical ventilation in Intensive Care Units. These concepts are the strenuous ‘hidden work’ needed to cope with care, the impact of the hostile environment, and the vulnerability caused by losing autonomy and an independent body. By understanding these elements and the ‘work’ undertaken by patients, which has previously been hidden to carers, we can begin to appreciate and support this activity.

4.1 Implications for practice

Our synthesis raises some important ideas for interventions that can support the ‘work’ undertaken by patients undergoing mechanical ventilation and informs future guidelines concerning the provision of patient-centred care on Intensive Care Units. Current guidelines focus on rehabilitation during and following Intensive Care and recommends patient-centred practice for adults with rehabilitation needs (NICE, 2009). These guidelines have little emphasis on what can be done as a measure to improve the experience of mechanical ventilation and reducing psychological distress. Our suggestions explain how and why suggested preventative strategies can improve the patient Intensive Care Unit experience.

Supporting the work that patients undertake through each stage of the trajectory should be an integral component in patient-centred care. Re-orientating patients to time and space and encouraging patient autonomy no matter how small could help to reduce feelings of alienation. Using familiar objects to make the environment less hostile, promoting a normal circadian rhythm through reduced lighting and the minimisation of disruptions during night hours (Kamdar et al, 2013), and using

technology to augment communication (Carruthers et al, 2017) are strategies that could facilitate patient work during ‘alienation’. This reorientation could allow patients to undertake more accurate ‘biographical work’ that have been previously distorted.

When considering patient-centred care for mechanically ventilated patients, health professionals need to be more aware of the strenuous ‘hidden work’ that takes place which is largely invisible, but nevertheless mentally and physically exhausting for patients. A greater recognition of the mental and physical ‘illness work’ that patients do to endure mechanical ventilation and other uncomfortable procedures such as weaning, endotracheal suction, injections and positional change should change the way in which such procedures are performed. Health professionals could facilitate this ‘work’ by routinely warning patients about procedures and suggesting ways that patients could prepare for, or assist with, procedures.

Health professionals can potentially influence the resilience of patients by providing verbal reassurance with signposting to any signs of clinical improvement, no matter how small, that indicate a transition towards recovery. Positive messages can foster hope and motivation giving patients the drive to engage with the ‘work’ of recovery. The ‘Biographical work’ that takes place means that patients also have to cope with thoughts about whether they will survive and, if they do, what their future might be. The level of resilience that patients have and levels of optimism or pessimism have the potential to impact on their recovery. Therefore, it is important to recognise the importance of encouragement from health professionals and family which can

contribute to the ‘inner strength’ of patients during mechanical ventilation (Alpers et al, 2012).

Guidelines and frameworks about patient-centred care for mechanically ventilated patients should consider the concepts of ‘personalisation’ and ‘trust’ within any recommendations. This review highlights the priority that patients’ place on having family members involved in their care and family members also value flexible visiting hours and being able to maintain vigilant attendance on loved ones in Intensive Care (Plakas et al, 2014; Karlsson et al, 2011). It is a practice that encourages a ‘personalisation’ of care by allowing the uniqueness of the patient to be more visible to health professionals. This review highlights that treating the patient as a unique person is a fundamental aspect of patient centred care in Intensive Care Units. Participants also needed to feel that they trusted health professionals and health professionals can nurture this by being seen to be vigilant in their care by patients. Future guidance, frameworks and educational provision on patient-centred care for mechanically ventilated patients should include strategies designed to nurture ‘personalisation’ of care for patients and build patient ‘trust’ in health professionals.

4.2 Implications for research

Future research should test interventions that can be used to foster patient-centred care and reduce levels of psychological distress that patients experience during care processes linked to mechanical ventilation to improve long term outcomes.

4.3 Strengths and limitations

This meta-ethnography provides a comprehensive account of patients' experiences of mechanical ventilation alongside key components of patient-centred care from the patient perspective. However, as searches were limited to published studies in English, there is a potential that some relevant studies either unpublished, or in other languages, are not included which may have affected our interpretations. There are also inherent limitations in any studies investigating the patient experience of mechanical ventilation as data is retrospective, researchers can only study the experiences of survivors and those with psychological distress are less likely to participate.

The strength of this synthesis lies in its breadth, methodological rigour and focus upon the patients' perspective of mechanical ventilation in Intensive Care settings; an element that has been somewhat neglected to date.

5. Conclusion

We have identified the first patient-centred trajectory model of the patients' experiences of mechanical ventilation in Intensive Care settings derived from a qualitative synthesis of international studies. Findings can be used to inform patient-centred care, policy, practice, guidelines and ongoing education for health professionals working in Intensive Care settings.

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Declaration

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Supplemental data 1: ENTREQ statement

Item	Response
1. Aim	To explore the patient experience of mechanical ventilation within Intensive Care.
2. Synthesis methodology	The review was informed by meta-ethnography because the included studies contained rich data and the development of new insight into the experience of mechanical ventilation was the intended output.
3. Approach to searching	A pre-planned exhaustive search was completed to seek all available published studies.
4. Inclusion criteria	<p>Population</p> <ul style="list-style-type: none"> Adult participants (aged 18 or above). <p>Study topic and types of intervention</p> <ul style="list-style-type: none"> The patient experience of mechanical ventilation in Intensive Care. This includes the experiences of treatments essential for mechanical ventilation including but not restricted to endotracheal and tracheostomy intubation, suction and weaning. Experiences related to care in a non-acute setting will not be included such as non-invasive respiratory support, Continuous Positive Airways Pressure or to long-term tracheostomy care beyond the acute care setting. <p>Study design</p> <ul style="list-style-type: none"> Articles reporting qualitative research involving both qualitative methods of data collection and analysis. <p>Language</p> <ul style="list-style-type: none"> English. <p>Year limits</p> <ul style="list-style-type: none"> No year limits were made.
5. Data sources	Eight electronic databases were used; MEDLINE, AMED, CINAHL, PsychINFO, Scopus, WileyOnline, PubMed Central, and the TRIP database. A hand search of the following journals was completed; Qualitative Health Research, Patient Education & Counselling, Nursing in Critical Care; Social Sciences & Medicine. A reference list search of all possibly relevant reviews was undertaken.
6. Electronic search strategy	<p>The following search terms were used for MEDLINE and amended for other databases:</p> <ol style="list-style-type: none"> MeSH heading: Critical Care TX 'mechanical ventilation' OR TX tracheo?tomy OR TX endotracheal* OR TX intubation OR TX suction TX qualitative OR TX interview* OR TX findings #1 AND #2 AND #3
7. Study screening methods	A review of titles and abstracts retrieved against the pre-determined inclusions criteria was completed by two reviewers. The full texts of those deemed possibly relevant were obtained and classified as 'relevant', 'definitely irrelevant' or 'unsure'; by two independent reviewers. Disagreements were resolved by a third reviewer.
8. Study characteristics	38 studies were included in the review detailing the experiences of 608 participants. Four research teams described different interpretations of data from the same participants in two articles namely Johnson et al (2006) and Johnson (2004); Logan & Jenny (1997) and Jenny & Logan (1996); Karlsson et al [2012a; 2012b]; Lof et al (2008; 2006). Both interpretations of the same participant data were included in the analysis as different aspects of the experience were reported and explored. Studies were conducted in Europe (n=19), North America (n=10), Australia (n=5), Asia (n=3), and South Africa (n=1). Years of publication ranged from 1994 to 2017. The method informing the included study was predominately phenomenology (n=22) but other designs were also used, namely grounded theory, ethnography, content analysis, case study and exploratory retrospective design. Details of data collection methods, data analysis and aims are provided in table 2.

9. Study selection results	4816 studies were retrieved from the search, 705 duplicates and 4050 studies were excluded due to the title and abstract not meeting the inclusion criteria. 61 full texts were obtained for review and 23 were excluded due to excluded populations (n=4), non-English language (n=1), conference abstract only provided (n=2), excluded design (n=4), findings not specific to mechanical ventilation (n=11) or duplication (n=1). The flowchart is available in figure 1.
10. Rationale for appraisal	Quality appraisal was completed to evaluate how the principles and assumptions underpinning qualitative research are reflected in the included studies informing the synthesis.
11. Appraisal items	The Critical Appraisal Skills Programme (CASP) qualitative checklist was used as it addresses the underpinning principles and assumptions of the study.
12. Appraisal process	Articles were divided between the research team and appraised. A sample of 20% were independently rated by all to measure inter-rater reliability.
13. Appraisal results	Papers were not excluded on the grounds of quality but provided an overview of the quality of the included studies as to ascertain the believability of results. The majority of included studies (n=28) achieved positive ratings on the checklist. The most common limitation throughout the literature was the relationship between the researcher and participants was not reported explicitly (n=27). Additionally, the procedures used to maintain rigour in the data analysis were not reported, or unclear, in 9 studies, and 8 studies did not explicitly consider how the data collections techniques addressed the research question.
14. Data extraction	Participant quotes, themes discussions and conclusions from the original authors were extracted onto NVivo by one reviewer. A second reviewer cross-checked paper versions independently. Data pertaining to the aims, methodology, theoretical perspective, sampling, data collection, analysis and interpretation were extracted by one author onto a Microsoft Excel spreadsheet.
15. Software	NVivo 11 and Microsoft Excel.
16. Number of reviewers	HC or TG extracted data onto NVivo 11 software. The second reviewer (FA and HC or TG) cross-checked paper versions. HC extracted information about the included studies onto the Microsoft Excel spreadsheet.
17. Coding	The authors began by importing concepts from seminal studies, which were identified by quality appraisal and the number of citations within the literature. Then, one reviewer coded subsequent texts line-by-line and a second reviewer coded paper versions.
18. Study comparison	In the first stage of analysis, themes were descriptive; then, constant comparison between studies was used to develop more generalised concepts than were found in the primary publications. These concepts were re-applied to the data to identify agreements and discord to synthesise the findings and create 'lines of argument'.
19. Derivation of themes	Inductive reasoning was used to develop the themes and subthemes from the concepts and lines of argument.
20. Quotations	Participant quotations and authors' interpretations are provided with the results section of the review to illustrate the themes and sub-themes. Further participant quotations and authors' interpretations are provided in table 4.
21. Synthesis output	New interpretations of the data have identified five themes with fifteen sub-themes. Three themes relate to the patients' experience of mechanical ventilation; alienation, hidden work and recovery. The themes are further explained in a conceptual model provided in figure 3.

Supplemental data 2: Search strategy

An electronic search strategy used eight databases; MEDLINE, AMED, CINAHL, PsychINFO, Scopus, WileyOnline, PubMed Central, and the TRIP database.

The search strategy for MEDLINE is outlined below:

5. MeSH heading: Critical Care
6. TX 'mechanical ventilation' OR TX tracheo?tomy OR TX endotracheal* OR TX intubation OR TX suction
7. TX qualitative OR TX interview* OR TX findings
8. #1 AND #2 AND #3

The search strategy for AMED is detailed below:

1. TX mechanical ventilation OR TX tracheo?tomy OR TX endotracheal* OR TX intubation* OR TX suction*
2. TX qualitative OR TX interview* OR TX findings
3. #1 AND #2

The search strategy for CINAHL is outlined below:

1. TX mechanical ventilation OR TX tracheo?tomy OR TX endotracheal* OR TX intubation* OR TX suction*
2. TX qualitative OR TX interview* OR TX findings
3. #1 AND #2

The search strategy for PsycInfo is outlined below:

1. TX mechanical ventilation OR TX tracheo?tomy OR TX endotracheal* OR TX intubation* OR TX suction*
2. TX qualitative OR TX interview* OR TX findings
3. #1 AND #2

The search strategy for Scopus is outlined below:

1. 'mechanical ventilation' (IN Title, abstract, keyword) OR tracheo?tomy (IN Title, abstract, keyword) OR endotracheal* (IN Title, abstract, keyword) OR intubation* (IN Title, abstract, keyword) OR suction* (IN Title, abstract, keyword)
2. qualitative (IN Title, abstract, keyword) OR interview* (IN Title, abstract, keyword) OR findings (IN Title, abstract, keyword)
3. #1 AND #2

The search strategy for Wiley Online is outlined below:

1. "mechanical ventilation" (IN Abstract) OR tracheo?tomy (IN Abstract) OR suction* (IN Abstract) OR intubation* (IN Abstract) OR endotracheal* (IN Abstract)
2. qualitative (IN Abstract) OR finding* (IN Abstract) OR interview* (IN Abstract)
3. 'Critical Care' (IN Abstract)
4. #1 AND #2 AND #3

The search strategy for PubMed Central is outlined below:

1. MeSH heading: Critical Care
2. TX "mechanical ventilation" OR TX tracheo?tomy OR TX suction* OR TX intubation* OR TX endotracheal*
3. TX qualitative OR TX finding* OR TX interview*
4. #1 AND #2 AND #3

A hand search of the following journals was completed; *Qualitative Health Research*; *Patient Education & Counselling*; *Nursing in Critical Care*; *Social Sciences & Medicine*. A reference list search of all possibly relevant reviews was undertaken.

Supplemental data 3: Quality appraisal of the individual studies

	Appropriate research design?	Appropriate recruitment strategy?	Appropriate data collection	Researcher-participant relationship considered?	Ethical issues considered?	Sufficient analytical rigour?	Clarity of findings?	How valuable is the research?
Alpers et al 2012	+	+	+	-	+	+	+	+
Arslanian-Engoren et al 2003	+	+	+	-	+	+	+	+
Chen et al 2009	+	+	+	+	+	+	+	+
Claesson et al 2005	?	?	-	-	+	-	?	?
Clukey et al 2014	?	+	+	-	+	+	+	+
Donnelly & Wiechila 2006	+	?	+	?	+	+	+	+
Engström et al 2013	+	+	+	-	+	+	+	+
Flinterlund & Andershed 2015	+	+	+	-	+	+	+	+
Forbes 2007	+	+	+	-	+	+	+	+
Fowler 1997	+	+	-	-	+	+	-	+
Hafsteindóttir 1996	+	+	+	-	+	-	+	+
Holm & Dreyer 2015	+	+	+	-	+	+	+	+
Jablonski 1994	+	?	+	-	+	+	+	+
Jenny & Logan 1996	+	?	+	-	+	+	+	+
Johansson & Fjellman 2005	+	+	+	+	+	+	+	+
Johnson 2004	+	+	+	+	+	?	+	+
Johnson et al 2006	+	?	?	-	+	?	+	+
Jordan et al 2002	+	-	?	+	+	+	+	+
Karlsson 2008	+	+	?	?	?	?	+	+
Karlsson et al 2012a	+	+	?	+	+	+	+	+
Karlsson et al 2012b	+	+	+	+	+	+	+	+
Locsin et al 2013	+	+	+	-	+	?	+	+
Lof et al 2006	?	+	?	-	+	-	+	?
Lof et al 2008	+	+	?	+	+	+	+	+
Logan & Jenny 1997	+	+	+	-	+	+	+	+
Patak et al 2004	?	+	+	-	+	+	+	+
Pattison et al 2009	+	+	+	-	+	-	-	+
Samuelson 2011	?	+	+	+	+	+	+	+
Schou & Egerod 2009	+	+	+	+	+	+	+	+
Sheen & Oates 2005	+	+	+	+	+	+	+	+
Sherlock et al 2009	?	+	+	-	+	+	+	+
Stayt et al 2015	+	+	+	+	+	+	+	+
Storli et al 2008	+	+	+	+	+	+	+	+
Tate et al 2012	+	+	+	-	?	+	+	+
Tembo et al 2015	+	+	+	-	+	+	+	+
Todres et al 2000	+	+	?	-	-	+	+	+
Wang et al 2009	+	+	+	+	+	+	+	+
Wunderlich et al 1999	?	+	?	-	?	?	+	+

Supplemental data 4: Coding report detailing the presence of data related to the stages and sub-themes

Stages	3.3.1 Alienation						3.3.2 Hidden Work						3.3.3 Recovery						
Sub-themes	Alienation	Being in a dependent body	Blurring of temporality and consciousness	Living in a hostile and unfamiliar environment	Losing one's voice	Loss of autonomy	Confronting death	Emotional work	Endurance	Mental Preparation	Possible futures	Resilience	Recovery	Perceptions of progress	Re-connecting with others	Regaining autonomy	New Perspective	3.3.4 Personalisation	3.3.5 Trust
Alpers et al (2012)	✓								✓		✓			✓				✓	✓
Arslanien-Engoren & Scott (2003)		✓					✓		✓			✓	✓					✓	✓
Chen et al (2009)		✓		✓				✓		✓				✓			✓	✓	✓
Claesson et al (2005)		✓	✓					✓											
Clukey et al (2014)		✓	✓						✓	✓								✓	
Donnelly & Wiechula (2006)		✓			✓					✓									✓
Engstrom et al (2013)		✓	✓	✓	✓									✓	✓	✓		✓	✓
Flinterud & Ambershed (2015)		✓	✓	✓	✓				✓					✓		✓		✓	✓
Forbes (2007)	✓	✓	✓				✓		✓	✓		✓	✓			✓	✓	✓	✓

Fowler (1997)		✓	✓		✓			✓	✓									✓	✓
Hafsteindottir (1996)		✓	✓	✓	✓									✓		✓		✓	✓
Holm & Dreyer (2017)		✓	✓	✓					✓							✓		✓	✓
Jablonski (1994)	✓	✓	✓		✓		✓	✓	✓	✓	✓						✓	✓	✓
Jenny & Logan (1996)	✓	✓	✓	✓	✓				✓	✓	✓	✓	✓	✓				✓	
Johansson & Fjellman-Wiklund (2005)		✓	✓			✓		✓						✓			✓		
Johnson et al (2006)		✓	✓				✓												
Johnson (2004)		✓		✓						✓					✓	✓		✓	✓
Jordan et al (2002)		✓		✓			✓			✓				✓		✓	✓	✓	✓
Karlsson et al (2012a)		✓	✓	✓		✓	✓		✓			✓	✓	✓		✓		✓	✓
Karlsson et al (2012b)		✓	✓	✓				✓				✓	✓	✓				✓	
Karlsson & Forsberg (2008)	✓	✓	✓	✓	✓											✓	✓	✓	✓
Locsin & Kongsuwan (2013)		✓	✓	✓		✓	✓				✓	✓	✓			✓	✓	✓	✓
Lof et al (2008)		✓	✓			✓	✓	✓								✓	✓	✓	✓
Lof et al (2006)		✓	✓	✓				✓										✓	

Logan & Jenny (1997)	✓	✓		✓					✓	✓							✓	✓	✓	✓
Patak et al (2004)					✓														✓	✓
Pattison & Watson (2009)	✓	✓	✓		✓	✓		✓	✓					✓	✓	✓			✓	✓
Samuelson (2011)	✓	✓	✓	✓	✓	✓	✓	✓							✓				✓	✓
Schou & Egerod (2008)		✓	✓	✓				✓											✓	✓
Sheen & Oates (2005)		✓	✓	✓		✓		✓			✓					✓		✓	✓	
Sherlock et al (2009)		✓			✓			✓	✓						✓					✓
Stayt et al (2015)		✓			✓				✓						✓				✓	✓
Storli et al (2008)		✓	✓	✓		✓	✓					✓			✓			✓	✓	
Tate et al (2012)		✓	✓	✓	✓			✓				✓							✓	✓
Tembo et al (2015)		✓	✓	✓	✓	✓										✓				✓
Todres et al (2000)		✓	✓	✓	✓	✓	✓	✓	✓						✓	✓	✓		✓	✓
Wang et al (2009)	✓	✓	✓	✓									✓					✓	✓	✓
Wunderlich et al (1999)		✓			✓			✓				✓							✓	✓

Supplemental data 5: Patient quotes and concepts from original studies related to the themes and sub-themes

<p>Theme 1. Alienation</p> <p><u>Being in a dependent body</u> “I couldn’t even turn round, just lift my shoulder. Continually having people helping me, putting pillows, and after five minutes I had to ask for help again and I felt tiresome in a way” (Engström et al, 2013) “When I woke up I had the tube down my throat and I had to depend on the [ventilator] and all the drips and tubes for my very life. It was terrifying at first, because I couldn’t help thinking, ‘What if something goes wrong with one of these machines, and nobody knows?’” (Johnson et al, 2006)</p> <p><u>Blurring of temporality and consciousness</u> They lacked the ability to orient themselves to time and place and felt helpless. They were not always sure what was going on. One patient said: “I was never really awake or able to orient myself to where I was. I couldn’t turn myself in bed to see where I was” (Schou & Egerod, 2008)</p> <p><u>Living in a hostile and unfamiliar environment</u> Patients reported that noise levels were very disturbing in the intensive care unit, and greatly affected their emotional state and sleep patterns. “The sound of the alarms continually plays off in my mind; sometimes I wanted to close my ears and eyes in order to forget about it” (Jordan et al, 2002) “I woke up and the curtains were drawn between our two beds ... it was a blood-curdling type screaming ... but luckily my nurse was there ... and I can remember she touched me, held my hand and said not to worry, that just that the little girl next door had just died and then I can remember, I wished they’d pulled the curtains right round me</p>	<p>Theme 2. Hidden work</p> <p><u>Confronting death</u> Patient I narrated at 3 months of being in a state of ‘giving up’. He did not think that he would survive another operation, so he felt that his life was threatened when the doctor told him that an operation was his last chance of survival. (Löf et al, 2008) Patients reported an awareness of their own mortality while on the ventilator, they realised that their survival depended on God’s grace alone and viewed prayer as an important component in overcoming the disease process and the intensive care environment. (Jordan et al, 2002)</p> <p><u>Possible futures</u> They wanted to get on with things and return to the ordinary daily life they had before they became ill. One informant, for example, said that she felt joy when she thought of going shopping together with her friend. The thought of company and social life also sparks the will to live but the most important goal is the family and a return to them. (Flinterud & Andershed, 2015) “I have no fear of dying, but always of being in pain and suffering even for 7 days past, still having a painful (body), the same pain, I would like to die instead. Two weeks past, I still suffered with the same pain. I thought that if (I) didn’t die soon, it would be pitiful.” (Locsin 7 Kongsuwan, 2013)</p> <p><u>Emotional work</u> She vividly recalled the first night when she was intubated. She felt sheer fear and anxiety compounded her breathlessness to the point that she had to be ventilated. From then on, she associated severe anxiety episodes with that and would hyperventilate during such episodes. (Pattison & Watson, 2009) Four participants reported a strong pervading sense of loneliness. This isolation occurred in relation to both</p>	<p>Theme 3. Recovery</p> <p><u>Perceptions of progress</u> Patients indicated that a perception of progress enhanced their ability to sustain hope and endure. (Logan & Jenny, 1997) When patients felt physical recovery, hope was instilled and this made it easier to look to the future and to a return to normal daily life. An example of this is in the following quotation: “So, concerning the strength and power, and when this strength returned relatively quickly, then you do not think about negative things. It is more a case of wanting to exercise and get started.” “Then you sort of feel almost like you are getting better. Now I am going home soon... and I am looking forward to going to the shopping centre.” (Alpers et al, 2012) Patients suggested that periods of no progress or plateaus were part of the trajectory of recovery. For many, feelings of depression and thoughts of death arose from their lack of visible progress. (Jenny & Logan, 1996)</p> <p><u>Re-connecting with others</u> The presence of family members was important for all of the participants in this study. A supportive relationship with family members seemed to be helpful for the patients. Through the many encounters of dealing with the aspects of impaired communication during the [respirator treatment] period, support given by a husband, daughter, or a friend helped the patients to master the situation. (Hafsteindóttir, 1996) They perceived that they were slowly getting back their own world and their own way of being. “I first thought I would make it and get out of there [Cardiac ICU], and that it would really happen,</p>
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<p>because at that point I thought, ooh ... and it wasn't so much that I thought oh gosh that's awful that little girl's died... I suddenly thought I could die, I'm somewhere where people die and I could die. (Todres et al, 2000)</p> <p>Informants also said that they felt as though they were "being viewed". The height of the bed (hip level), coupled with bouquets of flowers and relatives looking down on them, helped produce the ambiance of a funeral home. (Jablonski, 1994)</p> <p><u>Losing one's voice</u></p> <p>One participant recounted one difficult and scary situation: "Just then, I struggled a bit. It was so unreal to not be able to make a sound. It turned into a bit of a big deal. Yes, that's what it was." (Flinterid & Andershed, 2015)</p> <p><u>Loss of autonomy</u></p> <p>Perhaps the most vivid description of the helplessness associated with the inability to communicate came from David. He reported: "I was thinking, I don't want to live under these conditions you know. I was helpless, I was speechless." (Sheen & Oates, 2005)</p> <p>"I think any intensive care nurse – that's your fear – being intubated ... it's so upsetting ... at that time I still had control ... it's just the fact that once that happens, you've got no say, and having worked in intensive care, that patient then has got no say in anything that happens to them – everything is just taken away." (Todres et al, 2000)</p>	<p>physical and emotional aspects of their experience: "The worst was being left on my own, not being able to speak and being concerned that you were alone. No-one to help you". (Sheen & Oates, 2005)</p> <p><u>Endurance</u></p> <p>"You know, if you need it, and it does a good job and it helps you, I suppose the misery is worth it. But I would offer this as a good torture for Guantanamo." (Clukey et al, 2014)</p> <p>The patients, however, suppressed the urge to pull it out, and there were strategies for enduring the discomfort and agony: "Well of course it [the tube] is unpleasant to have, its no joyride, you know. But when one day had passed, I thought – well then it can stay there for a couple of days more. And when you have managed that, then you can do it..." (Holm & Dreyer, 2017)</p> <p><u>Mental preparation</u></p> <p>Several patients emphasized the need to be forewarned about unpleasant procedures so that they could be more mentally prepared for the discomfort. (Logan & Jenny, 1997)</p> <p><u>Resilience</u></p> <p>A positive attitude and positive goals were conducive to sustained work effort. Failure to progress required effort to avoid depression and included feelings of hopelessness. (Jenny & Logan, 1996)</p> <p>When the researcher asked if his positive attitude was of benefit to his recovery, he said: "of course it is! It is helpful to everybody; you will take the disease as a little frustration if you are positive." (Wang et al, 2009)</p>	<p>when I had the same nurse for a while, and we got to know each other." (Johnson, 2004)</p> <p><u>Regaining autonomy</u></p> <p>The individuals in this study gradually began efforts to reorient themselves, to pull themselves back into the "real world." (Forbes, 2007)</p> <p>Participants told of the many measures they used whilst on the mechanical ventilator to wrest back, or gain some control, over their treatments. Measures included tapping the pulse oximeter on the side of the bed or deliberately pushing things onto the floor in order to gain the nurse's attention, striving in a number of ways to initiate effective communication, and refusing to submit to treatments. Participants used these actions to indicate that they wanted some control over what was happening to them. (Johnson, 2004)</p> <p><u>New perspective</u></p> <p>"I know I was brought back from the brink of death, and I think it has to be for a reason. So where I go from here I don't know. But I've been given my life by my neighbor, my son who found me, my neighbor who helped me, and everybody who along the way has pitched in and helped. So step by step one day at a time. There has to be a reason for it." (Forbes, 2007)</p> <p>"I have revalued my time and intend spending more time with my family and grandchildren and children." (Johansson & Fjellman-Wiklund, 2005)</p> <p>"...I suppose it's safe to say that I'm not the same person as before." (Karlsson & Forsberg, 2008)</p>
<p>Theme 4. Personalisation</p> <p>Their manner meant something special for the patients and therefore they were remembered afterwards. They were described as nice, kind, gentle and helpful, showing interest in the patient's individual needs and life. (Alpers et al, 2012)</p> <p>"They [nurses] did just about everything they could to make me comfortable. In a lot of cases, they went out of their way." When asked what most helped her through the experience, one participant replied, "I guess good care; it's not something you pull through by yourself." (Logan & Jenny, 1997)</p> <p>"It was a female doctor who usually came to see me and another patient. And several doctors came. Especially the female doctor, she was so gentle and she smiled every</p>		

time she saw me. She was so gentle, and she often looked over the screen and said: “Hello”. (Alpers et al, 2012)
Even though it could cause frustration, patients felt that the nurses were attentive and patient. One patient was emotionally moved during the interview, talking about the nursing care: “Very good... And patient... I’m deeply impressed... It almost makes me cry”. (Holm & Dreyer, 2017)
(I actually expected that the sister would know better, especially since she nurses these types of patients every day ... the more I tried to explain, the more she appeared to be irritated and frustrated). (Jordan et al, 2002)

Theme 5. Trust

The goal for this interaction was to increase feelings of patient security. The nurse looked at the patient directly and said, “We’re out here in the hall and we won’t leave until you’re totally okay.” (Tate et al, 2012)
They noted that the physicians and nurses formed a trusting relationship with the patient. This resulted in the perception that they observed the participants closely and were more helpful to them. “I felt attached to this unit as if it was another home of mine. They helped in every way ... the doctor, I could recall when I started to feel tight in my chest, the nurse walked to me and checked on me very often to observe my condition. If my condition was worsening, she [the nurse] called the doctor. She [the nurse] constantly kept her eyes on me.” (Locsin & Kongsuwan, 2013)
“I felt that all the nurses were really attentive. Well, it’s just that I felt their presence there, around me all the time. I may not always have been able to see them, or even know them, but I just knew, or I felt that they were always close by.” (Johnson, 2004)